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"*A rough and swirling sea*": Voicing Amyotrophic Lateral Sclerosis through discourse analysis

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Abstract

Amyotrophic Lateral Sclerosis (ALS) is a rare, incurable neurodegenerative disease that leads to death within 5 years of diagnosis and greatly impacts patients' and caregivers' quality of life (QoL). Typically leading to death within 5 years, ALS underscores the need for emotional and psychological support. This study analyzes 118 testimonies from patients ($n = 67$), informal caregivers ($n = 41$), and formal caregivers ($n = 10$), with a gender-balanced sample ($n = 67$ women), using discourse analysis. Narratives reveal a complex emotional landscape of suffering and resilience, showing ALS as a disruptive force that prompts reevaluation of roles and life stories. Shared support is crucial within families and social settings. Many testimonies express a desire to raise awareness and fund research. Understanding ALS through these stories offers insights into the psychological, emotional, cultural, and social challenges, essential for developing tailored interventions to support psychological well-being.

Keywords

amyotrophic lateral sclerosis, quality of life, patients, caregivers, discourse analysis

Introduction

Amyotrophic Lateral Sclerosis (ALS), classified by WHO as a rare disease affecting 1 in 2000 or fewer, is a neurodegenerative disorder with unknown causes, no diagnosis, and no cure, that leads patients to death within 5 years of diagnosis (Abdulla et al., 2014; Lillo et al., 2012; Mezzapesa et al., 2007). It impacts physical and mental health, causing progressive loss of independence, respiratory and feeding issues, with an average lifespan of about 5 years.

The disease affects patients' quality of life (QoL) and caregivers' well-being (Galvin et al., 2018; Lillo et al., 2012; Radakovic et al., 2024; Yang et al., 2024). Patients may experience *locked-in* syndrome, impairing movement but not cognition (Feldman, 1971), and face communication, social, and physical challenges

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(Bremer et al., 2004). Psychological effects like depression and anxiety often result from awareness of disease progression and early mortality (Hogg et al., 1994; Kübler et al., 2005; Ozanne et al., 2013). Caregiving burdens affect family and professional caregivers' lives, with patients often needing specialized care in advanced stages, typically in nursing homes (Camargos et al., 2012; Poppe et al., 2022). The impact on well-being is like other chronic illnesses (Asbring, 2001; Bakker et al., 2013; Miyamoto et al., 2010; Ross et al., 1999). Uncertainty about disease progression and death, feelings of injustice, and physical and emotional isolation are common (Glozman, 2004; Grabler et al., 2018; Ozanne et al., 2013). Patients may feel guilt for burdening families but also find meaning in their disease, cherishing daily moments, and helping others (Grabler et al., 2018). Family narratives highlight disease meaning, life changes, family dynamics, and loneliness, with caregivers often prioritizing patients' needs (Bolmsjö and Hermerén, 2001; Cipolletta and Amicucci, 2015; de Wit et al., 2019; Galvin et al., 2016, 2018, 2020; Olesen et al., 2022; Yang et al., 2024). A gap exists in understanding formal caregivers' experiences. Previous studies have mainly analyzed testimonies superficially and in terms of words, without exploring how they are socially constructed. Language shapes meanings, identities, and positions (Davies and Harré, 1990). Discourse analysis helps us examine these processes, moving beyond the text to see testimony as a socially constructed practice (Schutz, 1970). Our previous study (Zambetti et al., forthcoming) used Emotional Text Mining (ETM; Cordella et al., 2014; Greco, 2020) to analyze testimonies, revealing four communication dimensions—management, care, support, and effort—and five thematic clusters, such as disease onset, difficulties, coping, and needs. This work focused on a secondary level analysis to explore the psychological, emotional, and social aspects of ALS through discourse analysis (Ruiz Ruiz, 2009). This analysis will try to add a new perspective and enhance ongoing discussions, viewing testimony not just as a produced text but as an integral social practice (Ruiz Ruiz, 2009).

Methods

Data collection

A total of 118 spontaneous testimonies in Italian[1] were collected from 38 websites, including public associations (e.g. conSLAncio Onlus), forums and blogs (e.g. Revert Onlus), and online newspapers (e.g. State of Mind). Of these, 67 were written by ALS patients, 41 by informal caregivers (family and friends), and 10 by formal caregivers (healthcare workers or researchers without personal relations with patients). Testimonies were equilibrated by gender (56.78% women, $n=67$). In Italy, ALS patients are cared for by the National Health Service, with a multidisciplinary approach. Care is free and includes a central role for families in daily management and cooperation with healthcare professionals. Alongside the public system, private facilities offer residential or semi-residential services.

This study does not directly involve people but analyzes testimonies that are spontaneously produced and voluntarily posted online, accessible to anyone with an Internet connection. Since no participants were recruited, and no sensitive information is present, the study does not require ethical approval. However, the research was conducted following the ethical principles outlined in the Declaration of Helsinki, and written testimonies posted online were made completely anonymous by the authors of this study, removing any names or references to places and people.

Data analysis

A discourse analysis (Ruiz Ruiz, 2009) was conducted on the 118 testimonies, following the identification of 4 communication dimensions and 5 general themes using ETM (Cordella et al., 2014; Greco, 2020; see Zambetti et al.,

forthcoming).[2] The texts were interpreted using Ruiz's qualitative model to explore the meaning of ALS experiences, connecting the narratives to the social context of the individuals who wrote them (Ruiz Ruiz, 2009; Schutz, 1970). This approach allows for a comprehensive examination of discourse, offering new insights into the psychological aspects of physical illness (Potter, 2003) and encouraging critical reflection (Parker, 2013).

Unlike linguistic, pragmatic, or semiotic approaches, the discourse analysis framework by Ruiz Ruiz (2009) stands out for its solid methodological base and psychosociological grounding. Ruiz defines discourse as "*cualquier práctica por la que los sujetos dotan de sentido a la realidad*" (Ruiz Ruiz, 2009: 2; translated: "any practice by which subjects give reality with meaning") highlighting its role in the symbolic and socially constructed understanding of reality (Schutz, 1970). His model includes three interconnected levels: textual (structure, language, rhetoric), contextual (link between discourse and its production setting), and interpretative (discourse as expression of ideologies and collective meanings). This method adopts an abductive approach to generate interpretive hypotheses based on both data and theory. Beyond describing texts, it uncovers latent meanings, identities, and social constructs (Ruiz Ruiz, 2009), including the ideological or subjective dimensions—how individuals perceive and represent the world. This analysis helped identify the narrative strategies used to evoke emotion and convey the impact of ALS, revealing gaps in existing literature within a strong theoretical framework (Alvesson and Kärreman, 2007).

The analysis focused on 250 text excerpts that emerged from the previous study (Zambetti et al., forthcoming) as elementary contexts with higher weights in the cluster (Lancia, 2012). This allowed for specific reflections for each theme that emerged, but more importantly, general reflections that led to the identification of distinctive narrative elements.

Results

ALS different conceptions

Patients and caregivers see ALS differently, and perceptions shift by disease stage. The acronym ALS has another meaning behind it, discovered through an initial textual analysis of the narratives (Ruiz Ruiz, 2009).

Early on, after diagnosis, ALS (*SLA* in Italian) is redefined as "*Stronza Lentamente Armata*" ("Slowly Armed Bitch"), viewed as a traumatic event disrupting lives. Terms like "*sciabolata in pieno viso*" ("slash to the face"), "*condanna a morte*" ("death sentence"), "*un mare agitato e vorticoso*" ("a rough and swirling sea"), "*un nemico*" ("an enemy"), and "*la Stronza. . .Fetente*" ("the Bitch. . .the Stinker"), which, when it passes, it devastates everyone, imprisoning the bodies , and forgives no one, show negative emotional impacts. ALS, burning into daily lives, is perceived as an unknown *enemy* that must be fought, but against which they have no efficient arms; patients and their families thus feel "*nuotatori inesperti*" ("inexperienced swimmers"), unable to cope with this cruel fate. Fear, anger, sadness, and a sense of loss lead patients online for explanations and possible medical solutions to be able to slow the advance of ALS.

> Excerpt 1: "You are sick with ALS", I hear him talk about diagnostic difficulties, the use of drugs, reactions ... I feel my skin crawl. I read on the Internet that the majority die choking on their own mucus. In fact, before I had final confirmation from the neurologist, I had already read all about amyotrophic lateral sclerosis.

At a deeper level (Ruiz Ruiz, 2009), arising from psychological interpretation, these testimonies show how, in the early stages, ALS has a very high negative emotional impact, which causes a strong sense of panic, disorientation, thirst for knowledge, and struggle to ask for explanations of confusion over medical terms.

However, it seems that in the later stages of the disease, support from family, social networks, spirituality, and religion foster a more

hopeful outlook, with a new awareness that seems to arise in patients and caregivers. The ALS acronym began to change in meaning toward a positive and hopeful point of view, becoming "*Sperare Lottare Amare*" ("Hope Fight Love"). They begin to talk about a "new life" characterized by ever-changing adventures in which to put themselves on the line, because ALS is "*soltanto una nota a piè pagina nella mia storia*" ("just a footnote in my story"), something one is forced to live with, but which should not take over even the non-body aspects of one's life. Because of this new awareness, contextualized within one's life and social situation (Ruiz Ruiz, 2009), patients adapt, finding hope, love, and meaning, transforming their perspective and appreciating life's small moments despite the challenges.

See Excerpt 2 and 3 in Supplemental materials.

This perspective provides an alternative framework for perceiving and engaging with ALS. Although ALS requires active fighting, it can also provide learning opportunities, exemplified by patients and caregivers who value life's small pleasures more.

Themes

Five themes emerged from testimonies: disease onset, difficulties, medical examinations, to cope, and needs. Each was analyzed through terminology and a psychological lens within the socio-cultural context (Ruiz Ruiz, 2009; Schutz, 1970).

Disease onset. People first talk about how the illness began, the *disease onset*. Patients and caregivers talk about the initial symptoms and premonitory events that were only later linked to ALS. Initial difficulties relate to feeling "*sempre più stanco e debole*" ("more and more tired and weak"), having joint pains that cannot be attributed to specific causes, difficulty in enacting the simplest daily actions, such as opening the water bottle or closing the buttons on one's daughter's onesie that become "*impossibili da gestire per la mia mano destra*" ("impossible for my right hand to handle"). All these symptoms begin to raise some doubts in them, which then leads them to consult general practitioners or specialists in neurodegenerative diseases. The first thought is never that of ALS: "*L'ipotesi della SLA non mi era mai passata per la testa*" ("The ALS hypothesis had never crossed my mind").

The connection between symptoms and ALS and the awareness of what was happening forced them to *open their eyes* and admit—because acceptance is a difficult next step—what was happening in their lives. These memories are often related to the narration of manifested symptoms, now seen from a different perspective, and to which they can finally explain.

> Excerpt 4: I remember well the moment when I had to admit that Dad was really sick. It was a late summer evening [. . .] My father, an athletic and healthy 58-year-old man, opened the front door breathlessly and sat on the couch, because the flight of stairs to get into the house, had destroyed him.

Many feel overwhelmed by despair, fear, and loss, affecting both patients and loved ones, raising concerns about not seeing children or grandchildren grow up or aging together with a partner.

> Excerpt 5: I walked out of the neurologist's office, sat down and cried. Everyone knows the dreaded prognosis of 2-5 years. I kept repeating it in my mind. 2-5 years will take me to see my daughter turn 9 years old.

They consider the need for psychological and social reorganization, and the need to accept the new role imposed by life, learning to see oneself "*classificata in questa categoria*" ("classified in this category"), often as one is "*l'unica persona della famiglia che se ne occupa*" ("the only person in the family who takes care of him").

After initial trauma, some find hope and "*sentirsi ancora vivi*" ("still feel alive") despite ALS, who seem to have been born just after

internalizing and accepting the disease as part of their lives. Indeed, are reported convivial family moments and strategies adopted early on to try to make up for physical shortcomings as soon as possible. One example is the use of an eye communicator combined with a speech synthesis program: "*oltre ad aiutarmi tra adulti mi permette di dialogare con il nipotino di tre anni e questo è bellissimo e mi permette anche di insegnargli a contare*" ("so in addition to helping me between adults it allows me to converse with my three-year-old grandson, and this is beautiful and also allows me to teach him to count"). Help also seems to come from a strong spiritual or religious attachment, which, through viewing life as a divine gift, an opportunity for growth, and a path to a higher reality, enables patients and caregivers to allow the burden of illness with less fatigue.

See Excerpt 6 in Supplemental materials.

The onset of ALS marks a turning point, dividing life "*before*" and life "*new*." This new chapter involves a situation from which there is no turning back, leaving individuals to navigate by tapping into their deepest, often unrecognized resources. It's described as vastly different from the life once envisioned for oneself or loved ones. The disease's limitations are emphasized, highlighting activities like running, walking, and social engagement that are no longer possible. Nonetheless, patients and caregivers must learn to live with the disease from its beginning, rediscovering the beauty around them and still enjoying the best that life offers, as the saying goes, "*godere ancora del meglio che ti riserva la tua vita*" ("still enjoy the best that your life holds").

Difficulties. Emotional and physical difficulties, often metaphorically expressed, grow with the loss of abilities, leading to anxiety and depression. Although ALS is a physical disease, the impact on the psychological level of all the motor difficulties involved is high:

> Excerpt 7: It is brutal to perceive that you are losing your body day after day. One struggles to find reference points. One is afraid to ask questions and has difficulty understanding the answers.

When encountering new difficulties, the most common feeling among patients and caregivers is that of

> Excerpt 8: Lost like lost luggage, extinguished like abandoned embers, crumpled like calendar sheets. Bodies exhausted, whipped by judgments, diagnoses, useless words. Chained in the depths of a cave, Plato's cave, where even the head and neck, as well as the limbs, are locked, and the eyes can only stare at the wall before them.

Thus, the feeling of *disorientation* returns to this theme. As far as familiars are concerned, panic and confusion manifest especially when thinking about the future and trying to hypothesize possible solutions to what will be "*il prossimo scoglio da affrontare*" ("the next obstacle to face"). The thought in caregivers' minds is: "*Cosa posso fare io, se lei non riuscirà più a scrivere e comunicare, come potrò aiutarla?*" ("What can I do, if she can no longer write and communicate, how can I help her?"). Sometimes these negative feelings prevail, and thoughts of death and wanting to give up emerge. Caregivers struggle with uncertainty about supporting loved ones as their communication deteriorates, sometimes contemplating death as relief.

See Excerpt 9 in Supplemental materials.

The feelings of disorientation and confusion are often narrated along with the feeling of *loneliness* and *abandonment* by institutions: "*soli, persi, nuotatori inesperti in un mare agitato e vorticoso*" ("alone, lost, inexperienced swimmers in a rough and swirling sea"). A concise sentence that nevertheless has the power to clearly summarize the feelings that are associated with most ALS patients and their families throughout the disease.

However, knowing that there is a family close by is what can make patients and caregivers "emerge" from these dark thoughts: "*e il giorno dopo mi tolgo il pigiama soltanto poco prima che i bambini tornino da scuola*" ("and the next day I only take off my pajamas just before the children come home from school").

But, patients and caregivers try to find reasons to live: they start to help other patients, donate to research, start to volunteer, create a social page, or publish a book to "*Creare una community, fare rete con chi vive la stessa esperienza, sentirsi meno soli*" ("Creating a community, networking with those going through the same experience, feeling less alone"). In this theme emerges how out of difficulties can come a strength that people didn't think to have, which allows them to move forward, and even "*perdendo pezzi di sé*" ("losing pieces of ourselves"), they continue to struggle, because "*si sa, solo che chi si ferma è perduto*" ("it is known, only that he who stops is lost").

Medical examinations. ALS also involves prolonged, frustrating medical exams to rule out other conditions, lasting months or years, and involving numerous tests and visits. These evoke feelings of heaviness, frustration, and uncertainty, not only in early stages but throughout the disease. Patients must undergo different types of examinations (e.g. blood tests, MRIs, CT scans, etc.) to exclude any kind of pathology that has physical symptoms like those in the early stage of ALS.

See Excerpt 10 in Supplemental materials.

This technical and explanatory theme at the narrative level focuses on the bodily aspects related to clinical and medical examinations. However, if one analyzes in depth the words chosen, emotional elements emerge in this theme as well, transferred to the reader. Terms such as "*calvario*" ("calvary"), "*incertezza*" ("uncertainty"), "*indeterminatezza*" ("vagueness"), "*ripetute più volte*" ("repeated several times"), "*decine di visite*" ("dozens of visits"), and "*numerosissimi prelievi*" ("numerous withdrawals") convey to those reading the testimonies a sense of heaviness, frustration, and endless time concerning what patients and their caregivers face.

The physical and emotional difficulties underlying the medical examinations are not typical only of the early stages. During the months following diagnosis, and throughout the disease, patients are forced to perform "*un susseguirsi di visite*" ("a succession of visits") aimed at maintaining life support (e.g. assisted mechanical ventilation, nutrition pump, aspirator, and cough machine), social interaction, and patient autonomy (e.g. alphanumeric table, eye communicator, or speech synthesis program).

> Excerpt 11: Every two months I have check-ups: blood tests, spirometry, pulmonary examination, cardiology examination, and dietary examination, carried out by doctors with whom I have a very pleasant relationship.

See Excerpt 12 in Supplemental materials.

To cope. Patients and caregivers also want to try to bring out a practical implication in their stories. They share coping strategies, different among patients and caregivers and the stage of the disease. put in place to overcome or "*convivere*" ("live together") with ALS.

Some patients use irony as an emotional survival mechanism in fighting against ALS: "*No, no, devo reagire con armi che la Fetente non conosce: l'ironia, il sorriso, già . . . il sorriso*" (No, no, I have to react with weapons that the Stinker does not know: irony, the smile, yeah. . .the smile"). Such behavior is enacted as a defense mechanism against possible negative emotional outcomes, such as anxiety or depression. Those who implement this strategy agree that "*bisogna esorcizzare con la leggerezza, l'umorismo . . . ridere della Fetente*" ("we must exorcize with levity, humor. . .laughing at the Stinker), as the only way to survive.

Along with humor and irony, another important element is the love of loved ones, whether family, friends, or colleagues:

> Excerpt 13: And then you have to have someone who loves you, because we are the relationships we have; alone and isolated we become objects, which no longer have any chance to make sense of the things that happen.

Family support and social relationships are perceived as "*il vero sostegno*" ("the real support"), which allows them to maintain that

"*normalità [. . .] ogni giorno nei rapporti umani*" ("normality [. . .] every day in human relationships"). Social support is thus characterized as vitally important, helping to reduce at least some difficulties. The closeness of friends, relatives, colleagues, and associations helps patients and their families feel less alone, as they belong to a community that sees them, recognizes them as fragile and in need of help, and supports them.

Along with the warmth of relationships, technological support (e.g. eye communicators, NIV) is also crucial, helping patients improve their QoL both physically and relationally.

See Excerpt 14 in Supplemental materials.

Often, physical and emotional difficulties lead to negative emotions like fear, anger, helplessness, frustration, and escape desires due to ALS. Caregivers sometimes lack strength because they are unprepared, partly due to poor disease understanding and complex clinical language, and feeling abandoned by institutions:

> Excerpt 15: With this testimony I would like to remind you how from one moment to the next life can change and can confront you with challenges greater than yourself. Challenges that you can't always overcome and don't always know how best to deal with.

Feeling abandoned is another situation for which they need to find strategies to cope with. Strategies that often lead caregivers to improvise themselves as "*infermieri, psicologi, fisioterapisti*" ("nurses, psychologists, physical therapists").

Healthcare professionals (e.g. physicians, practitioners, and researchers) also develop strategies, investing in research for new drugs and therapies.

See Excerpt 16 in Supplemental materials.

These coping strategies, from various perspectives, are vital for maintaining well-being, family stability, without being overwhelmed by the disease, and advancing ALS research, aiming for a future cure.

Needs. A final theme concerns the different perceived needs related to ALS. Some of these needs, in particular, are reported with the goal of being highlighted, with the hope that they may also reach out to associations and institutions that care for the sick.

The predominant need within the narratives is the need for more social support for both patients and their caregivers, who often find themselves in medical functions for which they have little expertise. Families feel, as also emphasized in the other themes, *abandoned*, and perceive a disparity that varies from region to region. Indeed, there seem to be regions where patients are much more supported, and others where "*vengono negati i bisogni e le necessità di noi malati*" ("the needs and wants of us sick people are denied"), and different opportunities are offered to patients, as if "*siamo malati di serie B*" ("we are second-class patients") rather than others that are first-class patients.

The following testimony expresses and summarizes clearly what the needs of those living with ALS are:

> Excerpt 17: What does an ALS patient need? Assistance. Continuous, constant, competent. And to have someone next to him whom he trusts.

See Excerpt 18 in Supplemental materials.

The essential elements, therefore, refer to specialized clinical and medical care—both on a bodily and psychological level—and to the more relational assistance that comes from loved ones. Such elements summarize very well the wide range of physical and emotional needs of patients and their caregivers. These needs are considered important, especially because help at various levels would allow for "*garantire al malato il necessario perché lui e la sua famiglia possano condurre una vita dignitosa e serena*" ("ensure that the patient has what is necessary for him and his family to lead a dignified and peaceful life").

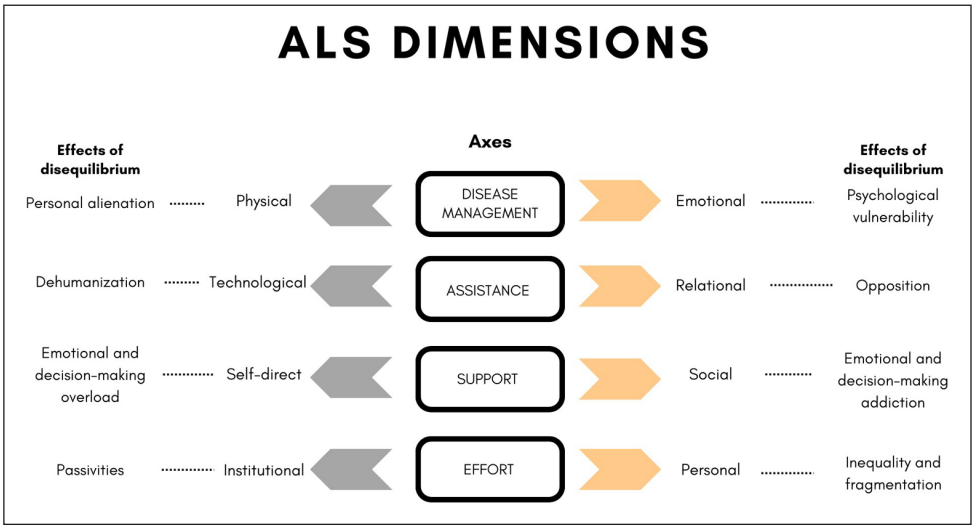

Figure 1. ALS factorial space in a continuum with two poles, and the related effects of disequilibrium.

In light of these needs, associations play a vital role in providing support, with many expressing gratitude and supporting donations for research development.

> Excerpt 19: AISLA [Italian Association of Amyotrophic Lateral Sclerosis]'s support is of immeasurable value not only to ALS patients but also to caregivers like me.

See Excerpt 20 in Supplemental materials.

Patients and caregivers also use social platforms like blogs or YouTube to share their stories, create a community, and get support remotely, from the more practical to the more emotional. Analysis of the testimonies thus reveals how the needs of ALS patients and their caregivers are not only, as is often mistakenly thought, physical, but also psychological. Only by offering integrated support of these two levels can we truly contribute to the promotion of their QoL.

ALS dimensions

This section analyzes the four ALS dimensions, summarized in Figure 1: disease management, assistance, support, and effort. These represent the implicit dimensions of communication and may apply to various ALS discourses (Cordella et al., 2014; Greco, 2020; Zambetti et al., forthcoming). Each is on a continuum between two opposite poles, where dominance can cause imbalance and disequilibrium.

Disease management. Patients and caregivers discuss physical and emotional management of ALS, related to its neurodegenerative effects: "*è difficile gestire una patologia più grande di me, sia a livello psicologico che mentale e fisico*" ("it is difficult to manage a pathology i.e. bigger than me, both psychologically, mentally and physically"). They agree that initial management is at the physical level, due to muscle weakness, inability to perform daily tasks, or breathe and eat independently in later stages, requiring machines.

See Excerpt 21 in Supplemental materials.

These physical implications, however, have a very strong impact on the psychological well-being of both patients and caregivers. Emotional challenges also must be managed, with patients and caregivers experiencing emotions (especially negative ones) that arise because of ALS, like: "*le emozioni e le sensazioni che stravolgono la vita*"

("the emotions and sensations that turn lives upside down"), "*le emozioni spiacevoli dalla coscienza*" ("unpleasant emotions from consciousness"), "*scatti di rabbia, paura, sconforto e rassegnazione*" ("shots of anger, fear, despondency, and resignation").

To be able to live despite the disease, and so to manage ALS as well as possible, many patients and caregivers report the importance of being able to find a balance between managing the body (physical part) and the mind (emotional part), because:

> Excerpt 22: A balance must be struck: rest and activity must have equal weight on the scale. Strong emotions also constitute an effort and worsen the condition of the sick person.

Patients should see themselves as integrated beings, not just bodies to cure or souls to listen to, aligning with Hippocrates' view that mind and body are inseparable and influence each other. Focusing on only one of the two aspects of disease management could lead to a suboptimal imbalance at the psycho-physical level. Overemphasizing physical management of ALS can lead to a situation of personal alienation of both patients and their caregivers. Patients might perceive himself or herself as only a body that needs to be cured—even if a cure does not exist—losing sight of the sense of self beyond the disease. A direct consequence could be poor motivation for treatment, precisely because one cannot see a way out. Caregivers, on the other hand, may feel that they are only as "tools" aimed at caring, curing, and supporting the patient. So, they couldn't perceive themselves yet as wives, husbands, or anything else beyond being a caregiver. Conversely, focusing solely on the emotional management of the disease, seeing as important only things like friendship, hope, and relationships, risks increasing psychological vulnerability, leading to anxiety and/or depression disorders, or burnout, even to the point of shutting themselves off to deal with the disease alone.

Assistance. Patients and caregivers emphasize the importance of technological tools (e.g. cough machine, PEG, respirator, etc) considered essential for improving QoL—"*ma soprattutto posso gioire di una grande soddisfazione che il male mi aveva tolto, merito di queste moderne tecnologie*" ("but above all I can rejoice in a great satisfaction that evil had taken away from me, thanks to these modern technologies")—alongside relational the "essential" support from loved ones, which helps cope with the disease in a different spirit and reduces loneliness: "*Se i legami sono saldi affronti meglio la malattia*" ("If the bonds are strong you cope better with illness").

> Excerpt 23: I have an incredible support network of family, friends and colleagues. I have been given the gift of perspective in life; I refuse to take a minute for granted. And I will not give up without a fight.

From the narratives, therefore, it emerges that, for an ideal of quality assistance, there is a balance between heart and technique, between listening and caring expertise, between humanity and technology. If assistance is perceived exclusively in its medical and technological side, could occur a sort of dehumanization of patient: they could be seen by caregivers as a clinical case, a number, or a protocol, and by themselves as a body to be cured for which must be kept alive to try to find out more about ALS. Once again, this situation could increase family members' and patients' feelings of loneliness and their non-involvement in the treatment, thus emptying care of its relational and social value. The patient care would thus become detached and "cold," where medical procedures are listed without conveying emotion or feeling. On the other hand, if assistance is perceived exclusively in its relational component, a kind of opposition to technology and drugs might take place, especially because of the desire to remain "human" and not become bodies that live only because of technology. In fact, patients report that they want to "*essere qualcosa di più che una malata di SLA*" ("being more than just an ALS patient"). This is mainly because there would be a tendency to perceive human warmth as the main component for a good life despite ALS, partly neglecting the usefulness of the medical and technological part.

Support. Alongside care, support is also perceived as an essential and indispensable element in the care of ALS patients and their families. Concerning this dimension, it emerges that the support perceived as necessary must derive, on the one hand, from oneself, and thus be self-directed, and on the other, from the social context within which one is embedded as a patient but also as a citizen. Self-directed support is narrated as the ability to not give up, relying on one's deep resources, which go beyond the illness, to handle problems independently, and not burden one's loved ones.

> Excerpt 24: Two expressions are very important to me: the first is "Carpe diem" (capture the day) because now I live in this moment and every single day counts for me. The second is "never give up" because almost anything is possible when you have the willpower or burning ambition to start and finish a project.

Personal strength seems to derive mainly from the ability to transform the negative emotions experienced due to ALS, and in particular anger, "*in energia per me e forza per gli altri*" ("into energy for me and strength for others"), to find a greater "*serenità [. . .] una sensazione di tranquillità*" ("serenity [. . .] a feeling of tranquility") that makes it possible to go on despite the disease. Self-direct support, however, is not sufficient to survive ALS, but it is also important to consider the social one. Social support is defined as all the different forms of help that patients and family members receive from outside, like from friends, colleagues, professionals, associations, and the general community. Associations are those that are most perceived as a source of social support and a new family.

> See Excerpt 25 in Supplemental materials.

Also, it is important that in the lives of patients and caregivers, there is a balance between their strengths and will to carry on, despite difficulties and illness, and the social support from other people and their community. Overemphasizing empowering oneself independently and strongly could lead to isolation and emotional decision-making overload, leading patients to feel on themselves all the burden of having to allow the disease, arising mainly from the "*vergogna e senso di colpa in particolare verso il familiare*" ("shame and guilt particularly toward the family member"), who must *sacrifice* part of his or her life to take care of the patient. On the other hand, requiring 24-hour care, patients need others' support. Conversely, focusing only on this side could lead patient's emotional decision-making addiction, thus depending on others even in personal choices, and also losing the remaining autonomy: "*la tua vita dipende totalmente dagli altri, in tutti i sensi*" ("your life is totally dependent on others, in every sense of the word"), and "*sai che il bisogno di essere aiutato oggi diventa una dipendenza per sopravvivere ed esprimersi domani*" ("you know that the need to be helped today becomes an addiction to survive and express yourself tomorrow").

As recognized by the narrators of these experiences of living with ALS, then, the right balance of support involves both a share of personal self-directed support and a strong social connection. Being able to rely on oneself but also knowing that one can count on others allows one to face difficulties more solidly and flexibly, looking beyond ALS. This, moreover, can have a positive impact not only on the patient but also on society.

> See Excerpt 26 in Supplemental materials.

Effort. The narratives show that there is a strong relationship between the support and the effort made to put it in place. Consequently, effort is identified in its two opposite forms: personal and institutional. Patients and caregivers said that personal effort is the set of resources that can come from the person, like: "*sorridere alla vita*" ("smile at life"), "*guardare al futuro con ottimismo*" ("looking to the future with optimism"), and "*godere di tante gioie della vita*" ("enjoy the many joys of life"). So, the key elements of personal effort are individual commitment, motivation, and sacrifice, but also trying to spread their own story and let others know

what ALS really is. This is precisely where the link is created between personal and institutional effort:

> Excerpt 27: Yes. Because what I am interested in [. . .] trying to grow the public role both in research and in the organization of services.

Thus, the importance emerges that a personal effort should also be followed by an institutional effort, both from the institutions that, through facilities, funds for care and research, and resources, also obtained through donations. In this way, it is possible to promote the deepening of the causes, consequences, and possible solutions to improve the lives of ALS patients and their caregivers and, in the future, perhaps arrive at a cure.

> See Excerpt 28 in Supplemental materials.

Although at the narrative and theoretical level, the importance of the institutional effort is recognized, patients and their caregivers sometimes feel that they are putting forth a great deal of personal effort, yet do not see the same effort put forth by society and the community. Doubts are expressed toward the "*Sistema Sanitario*" ("Health System"), which seems to be on *tilt* even for non-emergency situations and less serious diseases, thus contributing to an increase the "*Calvario, per il malato come per la famiglia*" ("Calvary, for the patient as well as the family"). The disproportion of positioning too much on the self-directed effort pole could cause a fragmented effort, where the many initiatives of individuals may remain isolated and not become systemic. Consequently, this would increase the inequality between those who have energy and thus can endure, and those who do not, and thus are left out. In fact, there are those who feel "*comunque un malato di SLA estremamente privilegiato*" ("however, an extremely privileged ALS patient") because of having "*una famiglia che mi aiuta, risorse economiche sufficienti per poter ricorrere a collaboratori esterni professionali*" ("a supportive family, sufficient economic resources to be able to use professional outside helpers"), and who instead perceives "*la disparità geografica*" ("the geographical disparity") that leads some patients to feel "di serie B" ("of second division"). On the other hand, if effort is exclusively seen as institutional, patients' and families' passivity could occur. They may perceive themselves as mere spectators, waiting for something in the system to change. Consequently, if this does not happen, feelings of frustration and disillusionment are likely, resulting in distrust of organizations.

> See Excerpt 29 in Supplemental materials.

Once again, for global patient care, and to put in place a true will for progress, the ideal balance would be to have both institutional and personal efforts. Only in this way can the conditions be created for each person to access but also actively participate in change, authentic, shared, and lasting, as is already happening in many associations.

ALS dimensions: Two different profiles. Considering the above, two opposite profiles can be identified (see Figure 2) that are configured based on positioning along the continuum of the four dimensions of ALS.[3] The first profile, highlighted in gray on the left side of Figure 2, is called the "technical, clinical-executive profile," as it encompasses predominantly technical, impersonal, and medical-institutional dimensions. People who place themselves in this profile see ALS predominantly as a medical and bodily aspect that must therefore be treated through the support of professional figures who are experts in the field. The approach implemented is therefore predominantly systematic and structured. However, the more relational and emotional dimensions are left in the background. On the contrary, the second profile, illustrated in orange on the right side of Figure 2, is designated as the "emotional, relational-community profile" due to its emphasis on the advantages of emotionally and relationally sharing the experience. People who place themselves in this profile see ALS predominantly as an affective, social, and relational disease, giving priority to these aspects in the patient and

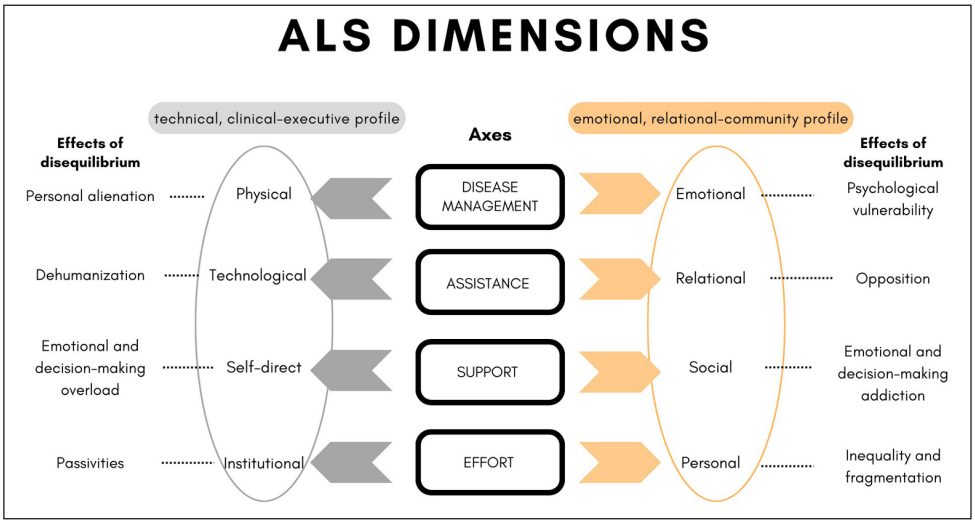

Figure 2. ALS dimensions and different profiles.

family care. The need to communicate emotions, maintain meaningful relationships, and feel part of a community is recognized as a major element. However, this approach tends to overlook the importance of support even at the body level and the need for continued research to help increase knowledge and improve care. As noted earlier, the ideal profile is precisely that which lies in the middle, where all dimensions are balanced at their two poles. This provides the ability to move toward one or the other pole, depending on the specific situation that requires it.

Discussion

Discourse analysis (Ruiz Ruiz, 2009) improved the examination of testimonies from ALS patients and caregivers. Most testimonies focus on negative feelings about ALS, like in previous studies (Olesen et al., 2022; Yang et al., 2024; Yu et al., 2014), but some also offer optimistic views on living with the disease, highlighting family support, associations, and inner strength. These narratives show how, despite critical conditions, individuals can positively share their experiences, as emerged in other studies and diseases (de Wit et al., 2019; Galvin et al., 2016; Yang et al., 2024). Most testimonies include emotional and rational components, addressing needs, efforts, and care related to ALS, especially around diagnosis, often depicting a rupture with the past as patients start a new life. Future research should explore what enables ALS patients and families to persevere. Most narratives are informal, expressive, and aim to raise awareness and support research, driven by a desire to validate the disease and advocate for affected individuals. Personification, such as calling ALS the Bitch or death sentence, evokes strong emotional impact.

These narratives help patients and caregivers articulate and redefine their identities, and this is also a crucial aspect in literature about diseases (Bert, 2009; Charon, 2017). Caregivers' testimonies often focus on technical aspects, with little about personal emotional experiences. Further studies should explore their perceptions and emotional responses. As shown in Figure 2, two opposing profiles emerge: the "technical, clinical" and the "emotional, relational" ones, with an ideal balance in the middle. The technical-clinical profile focuses on the physical and functional management of the disease and is based on the use of technology, clinical protocols, and organizational strategies to ensure safety, continuity, and efficiency

in caregiving. This approach has the potential to promote adherence to treatment, coordination with and among healthcare systems, and management of the complex needs of patients and caregivers. However, an excessive focus on these aspects of care may result in personal alienation and emotional exhaustion. Conversely, the emotional-relational profile is oriented toward the psychological and social dimensions, recognizing emotions and their reprocessing, mutual support, and the co-construction of relational networks. This approach has the potential to cultivate resilience and a sense of community belonging. However, an overemphasis on these aspects may result in an emotional burden, potentially leading to psychological vulnerability and resistance to treatments perceived as "cold" or invasive. Both profiles demonstrate a predilection for an efficient approach to ALS, and a combination of technical-clinical and emotional-relational dimensions is vital. A balanced profile would maintain clinical rigor without sacrificing the humanity of the caring relationship, promoting personal and relational well-being (Bolmsjö and Hermerén, 2001; Cipolletta and Amicucci, 2015; Olesen et al., 2022).

This study emphasizes on ALS's complex issues and the need for ongoing research, including more caregiver and patient interviews (Yang et al., 2024), particularly in the early or intermediate stages. A short scale based on the four dimensions of ALS discourses (see Figures 1 and 2) is being developed to assess and improve awareness, balance, and care, fostering a patient-centered approach that addresses both physical and psychological needs and strives to restore dignity. The goal is to better analyze these profiles to design ad hoc interventions. The findings show the importance of creating personalized support for ALS patients and caregivers. This could include psychological support, self-help groups and stress management for both formal and informal caregivers. Digital platforms could also be used to provide remote monitoring, information, support, and networking. The aim is to adopt an integrated, multidisciplinary approach that addresses practical and emotional needs. The findings will also inform practices and interventions by service providers involved in the care network. These providers can facilitate communication and ensure continuity and personalized care. Training programs and reference figures (e.g. case manager) could improve access to resources, reduce loneliness and overload, and disseminate further knowledge of ALS, reducing social isolation and caregivers' stigma (Charon, 2017; Trail et al., 2003).

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Ethical considerations

This study analyses online testimonies that are in the public domain. The research was conducted following the ethical principles outlined in the Declaration of Helsinki, and written testimonies posted online were made anonymous.

Following a preliminary review conducted via the platform of the Committee for Integrity and Research Ethics of the University of Bergamo, the research project was deemed "not applicable" for evaluation by the Committee, as it does not present any ethical or legal issues that require a formal opinion. This outcome is consistent with the Regulations of the Committee for Integrity and Research Ethics of the University of Bergamo (Article 3, paragraph 1, letter a, and paragraph 2), which establishes that only research involving individuals and/or with significant ethical implications are subject to ethical evaluation, excluding activities that do not implicate the direct involvement of human subjects, the use of sensitive personal data or experimental interventions, and research that takes the form of literature reviews or theoretical and methodological analyses. Therefore, in light of the official outcome of the preliminary review and the current regulatory framework, we can confirm that the project does not need to be evaluated by the Ethics Committee."

Consent to participate

This is a study that does not directly involve people but analyzes testimonies spontaneously produced and voluntarily posted online, accessible to anyone with an Internet connection. Since no participants were recruited, informed consent was not necessary.

Consent for publication

This is a study that does not directly involve people but analyzes testimonies spontaneously produced and already voluntarily posted online, accessible to anyone with an Internet connection. Since no participants were recruited and all the testimonies were already posted online, consent to publish was not necessary.

Author contributions

All authors contributed to the conception and design. Material preparation, data collection, and analysis were performed by Elisa Zambetti, supervised by Simone Belli and Andrea Greco. The first draft of the manuscript was written by Elisa Zambetti, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability statement

Research data is available upon request to the authors.

Supplemental material

Supplemental material for this article is available online.

Notes

1. The transcripts were analyzed using the original language to preserve tone. The excerpts' English translations were created later to facilitate comprehension.
2. In our preliminary study (Zambetti et al., forthcoming), we employed T-Lab software with a quantitative approach, using the Token, Hapax %, and Interclass Correlation Coefficient indices to extract main themes and implicit communication axes. This first phase is preliminary and provides an overview of the data. This process generated weighted text excerpts for each theme, which served as the basis for the secondary analysis presented in this article. In the second phase, we carried out in-depth discourse analysis using the Ruiz Ruiz (2009) scheme. This anchored the significance of the axes and themes to the specific culture of each testimonial, and allowed us to delve deeper into the data, and construct the profile map in this article.
3. For further information on the process of identifying axes and their respective dimensional poles, please refer to the article Zambetti et al., *forthcoming.*

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